Childhood Blindness in the Eastern Mediterranean and North Africa

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7.1 Introduction

The MEC is very diverse in terms of population sizes, wealth, levels of development, health programmes, culture etc. and, as such, reflects the whole spectrum of childhood blindness (CB) and its causes. (1) The demographic patterns in this region including the high U5MR in many countries are shown in chapter 5.

Changing Patterns

With the improvements in hygiene as a result of increases in the standard of living in most of the Middle East countries, the causes of CB have shown a marked swing away from acquired to congenital blindness in line with Western nations as revealed in studies over the past 25 years. (2), (3), (4), (5), (6), (7), (8), (9), (10), (11), (12), (13), (14), (15), (16), (17), (18), (19), (20)

After 1962, as a result of the WHO sponsored mass vaccination which eradicated smallpox, no smallpox keratitis leading to blindness was detected in any of the eastern Mediterranean countries. In addition, there was a corresponding decrease in the incidence of bacterial corneal ulcers. This could be related to a marked decrease in the incidence of measles with the adoption of vaccination. Bacterial keratitis may complicate the course of measles keratitis. (21)

The decrease in blinding infectious diseases has ushered in an increase in the incidence of genetically determined causes of blindness, which has been further accentuated by the high rates of consanguineous marriage; an accepted tradition in the region.

Whilst this shift from acquired to genetic causes of blindness has been relatively gradual in some countries, in those which have experienced a rapid increase in the standard of living, and

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consequent introduction of comprehensive health programmes, the period has been much shorter as, for example, in Saudi Arabia. (9), (10)

Prevalence

The percentage of CB among the estimated 3 million blind in the MEC is not known. (21).

Earliest Studies

The first study on CB in this region was that of Merin in Cyprus (2) in 1972 and this was followed by studies from Lebanon, (8) Saudi Arabia, (10), and Jordan. (3) All these studies have demonstrated a swing away from blindness as a result of bacterial infections, towards congenital causes as a result of an increase in living standards and the provision of health care over the last 30 years. Data from the rest of the MEC are scarce.

CHILDHOOD BLINDNESS BY REGION AND COUNTRY

7.2 Childhood Blindness in Cyprus

Merin's study in Cyprus was based on an examination of 112 past and present pupils of two blind schools on the island and examination of available members of the families with pedigree charts. (2) Ages ranged from 5 to 18 years for the current students and 20-40 years for the 53 past students. Findings revealed that blindness was due to hereditary causes in 79% of all students of which 50% were autosomal recessive (AR), and 12% and 13% each were autosomal dominant (AD) and sex-linked (XL) respectively. Multifactorial and uncertain modes of heredity and new mutations caused blindness in the remaining 25%. Predominant causes were Norrie's disease. albinism and Usher's syndrome. The study raised several interesting points: -

 a) Pre- and perinatal causes were much less in evidence when compared to studies in the UK, and hereditary causes much more so.

- b) Cyprus would appear to be a country modern enough to avoid acquired postnatal infections type blindness, but not so modern as to have late rubella or frequent resuscitation of infants in oxygen incubators.
- c) The proportion of hereditary causes of blindness in the present students were higher than in the past students.
- d) In Cyprus, autosomal recessive disease causes blindness four times as frequently as autosomal dominant disease, whereas in England and Wales, hereditary blindness is most frequently due to AD causes followed closely by autosomal recessive causes.
- e) Such an excess of AR conditions is usually found among populations with a high rate of consanguinity. As consanguinity is prohibited both by the Greek Orthodox Church and by local custom, it is conceivable that this high rate of recessive disease comes from the fact that the Greek population of the Cyprus villages is an endogamous one. For generations, people have married from their own villages thus creating a genetic effect similar to a population with a high consanguinity rate. This effect could be similar to that noted by Green et al in Newfoundland and Labrador.

7.3 Childhood Blindness in Eastern Mediterranean Arab Countries

7.3.1 Lebanon

The second work from the Eastern Mediterranean came from Lebanon in 1975. (8) Baghdassarian and Tabbara studied pupils in three blind schools in Lebanon between 1970-73 covering 231 children in the age range 6-20 years (the age of onset of blindness was 0-14 years). Of these, 70% were blind before the age of 2 (40% at birth), 77% of blindness was due to genetically determined with two thirds AR in inheritance as a consequence of the high consanguinity. Of the total number examined, 50% were the products of consanguineous marriages and 88 (56%) with genetic blindness

had a history of parental consanguinity compared to 28% with acquired blindness. The major causes of blindness were retinal degeneration (53 pupils), congenital glaucoma (36 pupils) and congenital cataract (34 pupils). Of the total number of hereditary conditions, two thirds were of the AR type.

7.3.2 Childhood Blindness in Jordan

Several studies have been undertaken in Jordan where nearly half of the population are Palestinians in origin (22) The rapid change in socio-economic conditions in the last 20 years, despite limited resources, has led to a marked drop in the infant mortality rate, an increase in the life expectancy at birth, and proper control of most infectious diseases through community and preventive medicine campaigns (3) This has been reflected in the changing pattern of CB in this country.

Causes

It is not surprising therefore that a study of 137 visually handicapped students blind and undertaken by Sayegh, Khoury and Arafat (quoted by Sir John Wilson) found that heredity was the main factor in CB contributing to 79% of cases with acquired causes trailing behind at 21%. (23) The commonest genetic causes were RP (23%) and cataracts (17%) and of acquired blindness were ocular infections (15%) and injury (4%). The rate of first cousin marriage in the parents of those affected by genetic blindness was 65% as opposed to 39% in the general population.

A more recent study in 1992 covered 260 Jordanians with CB and visual impairment and revealed that genetically determined causes in two generations were responsible for 122 cases (77.7%) of 157 subjects born after 1970 and in 69 (67%) of 103 subjects born before 1970. (3) This was considered a statistically significant change in the overall pattern of blindness between the two generations and also revealed a significant change in the pattern of acquired blindness alone. There was a decrease in corneal

infection as a cause of visual disability and blindness in the younger generation but this was accompanied by an increase in trauma.

Changing Patterns

Authors of the previous studies believed that their findings coincided with those of developed countries, with a preponderance of genetic causes and relative rarity of infections and disorders of malnutrition. They concluded that Jordan was a country modern enough to avoid the acquired causes of childhood inflammatory blindness and those of malnutrition, but not so modern as to have the late rubella syndrome or retinopathy of prematurity. The dramatic reduction in blindness from infection over a period of 30 years in Jordan demonstrates the role played by rising living standards and improved sanitation in the eradication of preventable diseases. This was counterbalanced by the equally dramatic increase in genetically determined diseases. (3)

Recommendations

Several recommendations were put forward which are: (3)

- 1. Organisation in Jordan of anti-consanguinity marriage campaigns by bodies such as governmental, religious bodies etc;
- 2. Enforcement of legislation for child protection in schools, streets, and at home to avoid ocular trauma;
- 3. Endorsement and development of safety measures in the school curricula;
- 4. Early detection of congenital cataract and glaucoma by general practitioners and paediatricians for prompt surgical intervention with proper optical correction; and;
- 5. Promoting the donations of local donor materials for keratoplasty.

7.3.3 The Palestinians: West Bank, Gaza and Israel

In Northern Israel

A study in Northern Israel between 1977-1989 of 193 children with severe visual deficits aged from birth to 4 years. (5) The population reported included the four main ethnic groups with the following proportions; Jews 66%; Moslems 22.5%; Druze 6% and Christians 5.5%. The author noted that the percentage of children of Muslim origin was higher than expected from their proportion in the community, whereas the percentage of other ethnic groups was proportional to their percentage in the community.

The study estimated an overall incidence of SVI of 1/1000 live births, although the ethnic specific incidence varies. All children were diagnosed within 20 months of birth with the deficit being first suspected by a family member in 33% of cases. Genetic aetiology accounted for 38%. Consanguinity among the Muslim group with genetically related aetiologies was 72%. In addition, despite the fact that consanguinity was higher in both the Druze (85%) and Christian (77%), there was an increased risk of genetically determined aetiologies in the Muslim population (66%) as compared to 14% in the Druze and 42% in Christians.

The frequency of pathological conditions in this study was: cataract 40%; ROP 33%; central blindness 27%; glaucoma 15%; optic atrophy 14%; Leber's optic atrophy 11%; chorioretinitis 1%; and retinal detachment (not associated with ROP) 1%. The aetiological distribution was; genetic 38.3%; prematurity 24.4%; infections 4.7%; traumatic 0.5%. There were 32.1% where the aetiology was unknown.

West Bank and Gaza Strip

Some 6 years after the completion of this of the author's survey, a further review of 205 children from the blind schools in the WB and GS found blindness in 63% and SVI in 21% with SVI. (24) Retinal conditions were the predominant aetiology at 52%; followed by optic atrophy 12%; glaucoma 9%; and cataract 7%. The minimum prevalence of CB was estimated at 0.32/1000 children which falls within Foster and Gilbert's rate for countries with low under-5 mortality.

7.4 The Arabic Peninsula

7.4.1 Childhood Blindness in Kuwait

In a study of 139,769 Kuwaiti students, (16) the percentage of defective vision was 0.099%. Hereditary and genetic aetiologies responsible for 75.5% of the cases. Recessive inheritance accounted for 36.2%, AD 34.3%, XL 9.5% and multifactorial for 20.0%. Among the hereditary conditions, 46.7% were the product of consanguineous marriages.

Inflammatory causes accounted for 20.9% of the total. The most important cause was neglected cases of mucopurulent and purulent conjunctivitis, resulting in corneal ulcers and the ensuing complications. This accounts for 62.1% of the total number of inflammatory causes. Trauma, metabolic disorders and neoplasia account for 3.6%.

7.4.2 Saudi Arabia

In Saudi Arabia, two studies were undertaken in the 1980s. The first was by Badr and Qureshi in 1983 in the Eastern Province and the second was Tabbara and Badr in a blind school in Riyadh two years later. (9), More recently, two more studies were published from Riyadh. (25), (26)

The Eastern Province Study

The first study incorporated 219 pupils and teachers (the ratio of pupils to teachers is not known but the age range is given as up to 60 years). In male students, the age of onset of blindness was highest in the birth to one year category (50 pupils), and 14 out of 15 female pupils were blind before the age of 10 years. The principal causes of blindness in the 204 males examined were; ocular infections 70.59%; congenital anomalies 15.69%; other causes 13.73%. Smallpox was the major cause of ocular infections (38.73%) followed by bacterial

infections (27.45%). Of the 15 females, 13 suffered from congenital blindness. In addition, 95% of those examined had evidence of trachoma. There was a history of parental consanguinity in 79% of the total number examined and in 66.6% of those with congenital anomalies. In 35.5% of the congenital anomalies group, there was a positive family history. It is difficult to draw strong conclusions from this paper as the age range and groupings are not given although the rate of parental consanguinity appears to be very high. (9)

Riyadh Study 1980

In this study 187 pupils of two blind schools in Riyadh blinded before the age of 14 years (70 (10), % before the age of 2 years) were examined. (10) Authors quote figures of 75% acquired blindness prior to 1962, changing to 84% genetically determined blindness after 1962. This study included 65 pupils born before 1962 and 105 born after 1962. (Table 7.1)

Mode of inheritance in the majority of the genetic disorders in the group was AR. In the group of genetically determined disease 56% were the product of consanguineous marriages while, in the group with acquired blindness, this figure was 14%.

The first group had an incidence of 18% blind before the age of 2 years but, in the second group, this figure had risen to 70%. The causes were found to be genetic in origin in 106 pupils and acquired in 57 pupils (it was not possible to determine the cause in 7). There was active trachoma present among some of the children but it was not the direct cause of blindness. (Table 7.1)

Eye Referral Centre Study

A more recent study of causes of CB in an eye referral centre in Saudi Arabia (5217 children, ages 2-18 years) revealed the pattern of blindness has changed again. (25) The prime cause of blindness has become optic nerve disease (40%) followed by retinal disorders (32%) and cataract (7%). Corneal causes have disappeared from the scene altogether. Trauma remains a prime cause of unilateral blindness (39%).

Genetically determined conditions remain a major contributory factor to bilateral blindness at 70% (n=37/53) versus 27% of unilateral blindness and has remained so. $^{(26)}$

Parents' consanguinity was present in 21% and 27% of children with blindness and visual impairment (3/60 to 6/18) respectively (including unilateral cases). In the genetically determined conditions, the figure rises to 27% (any blindness), and 46% amongst the visually impaired compared to 1-3% in the acquired cases (Table 7.1). Consanguinity remains an important contributory factor to blindness from genetically determined conditions especially in bilateral blindness. (25), (26)

Table 7.1 Childhood Blindness among 106 blind students in Saudi Arabia (9), (10)

Pre-1962	Post 1962
38%	33%
6%	29%
25%	16%
-	
25 (56%)	4 (33%)
16 (36%)	0 (0%)
2 (4%)	7 (58%)
2 (4%)	1 (8%)
	38% 6% 25% - 25 (56%) 16 (36%) 2 (4%)

ROP in Saudi Arabia

ROP was reported reported in Saudi Arabia and found to be comparable to reports from other parts of the world. (27) The incidence in pre-terms with birth weight of <1500 g and <1250 g was 41% and 50.7%. Nineteen of the 73 children with ROP (26% or 9.7% of all infants studied) reached threshold ROP. Modern treatment of the ROP with laser or cryotherapy is available and successful in inducing regression in all of patients.

7.4.3 Childhood Blindness in Oman

The only available information in Oman is on the prevalence of blindness in the 0-14 years age group, obtained through a population based study using stratified cluster random sampling procedure of 11,417 people. (28) The estimated prevalence of blindness in this group was 0.08%. Rubella cataract has recently been reported by Khandekar et al in a historical prospective cohort study that included review of 32 surviving patients with congenital rubella syndrome (CRS) between 1987 and 2002. (29) It appears that CRS poses a burden in Oman in view of the high prevalence of visual, audiologic, and neurologic disabilities. The age-adjusted prevalence of CRS was 0.073/1000 in the Omani population younger than 20 years, and the incidence was 0.6/1000 live births. (28) The main findings in these cases were cataract (n=11), retinitis (n=16), microphthalmos (n=6), and glaucoma (n=4).

The systemic associations in the 11 patients with cataract were hearing loss (n=7), cardiac anomalies (n=4)and neuropsychological anomalies (n=6) children. The functional outcome of cataract surgery in these patients, despite excellent eye care, was poor. The need for an effective immunisation programme was put forward by the authors.

7.4.4 Childhood Blindness in Yemen

There are no epidemiological studies on CB in Yemen where onchocerciasis is endemic. (30) The only available reports are on VAD. (31)

7.5 **African Arab Countries**

7.5.1 **Childhood Blindness in Egypt**

Egypt has different problems from others encountered in the North African part of the East Mediterranean region.

A survey of 113 people in 3 blind institutions in Mansoura in the North East Nile Delta was

carried out by El-Gilany. (32) More than half of the cases were in the age range 5-14 years. There were high proportions of both congenital and acquired conditions. The former accounted for almost half of the total number (48.7%), and the latter to 51.3%. The commonest of the acquired pathologies were corneal opacities at 32.8%, cataract 17.2%, optic atrophy 13.8% and glaucoma 12.1%. The commonest genetic causes were cataract 37.9% glaucoma 29.1%. Overall, bilateral corneal opacities, bilateral cataract, and bilateral glaucoma were the leading causes of blindness at 17.7%, 14.2% and 14.2% respectively. The striking finding in this study was that in two thirds (65.5%) of the total number, blindness had occurred before the age of 10 years.

In an earlier study in 1987, Kamel pointed out that the main causes of blindness in a blind school in Alexandria were congenital anomalies, followed by infection and trauma (quoted by El-Gilany). (32) The author concludes that health and social care for the group studied were inadequate and more than half would benefit from further (including management legislation keratoplasty). In addition, a registry of blind people and a nationwide community survey on the epidemiology of blindness was urgently needed.

Avoidable Blindness

Blindness due to avoidable causes was significantly higher among participants of low or very low social groups and more likely to occur in the older age groups. Traditional eye medicines were found to include lime juice, urine, toothpaste, kerosene, and breast milk. (32)

Trachoma in Children

A survey carried out in Egypt in 1979-80 by Korra et al found trachoma to be still highly prevalent in the rural population with peak prevalence among children between 2-6 years of age. Trachoma was often complicated by acute ophthalmia, and between 2-3 million new cases were received each year in the 300 hospitals with ophthalmic departments. (23)

7.5.2 **Childhood Blindness in Tunisia**

In Tunisia, hereditary causes also form the main bulk of blindness in the country as seen in a study of 214 children living at the Blindness Institute of Bir El Kassaa. The main cause, however, and different from the rest of the Arab world, being congenital glaucoma instead of retinal dystrophies. The latter came second followed by CC. Like others in this region, the high rate of consanguinity in the community was the cause. (17)

7.5.3 Childhood Blindness in Sudan

Prevalence

Childhood blindness in Sudan is most probably the worst in the Arab world, yet studies on the prevalence are very scarce. There are no epidemiological studies on this problem among Sudanese children. Most recently, Abdu et al (33) studied the subject in refugee camps for displaced people in Khartoum. They found a prevalence of CB of 3% and VI in 5%. The prevalence of blindness was 1.4/1000 children.

Causes

Corneal causes were the predominant aetiology in the study accounting for 40% of blindness followed by the lens (12.5%), retina (7.5%), whole globe (5%), optic verve (2.5%) and glaucoma (2.5%). Nutritional factors were the main contributory cause of corneal pathologies in 2.5% of cases, trauma in 10% and measles in 7.5%. (33)

7.6 **Predominantly Muslim Countries**

7.6.1 Childhood Blindness in Uzbekistan

Demography

Whilst technically outside the area covered in this final section, being in Central Asia, Uzbekistan was included in the Middle East Crescent by the World Bank in 2000. (34) The population is made up of Uzbeks (71.4%),

Russians (8.3%), Tajiks (4.7%) and Kazakhs (4.1%). These and other ethnic groups reflect the numerous migrations, trade routes and conquests that have affected this area. (4)

Prevalence and Causes

A study in 1999 covering 7 blind schools spread throughout Uzbekistan evaluated 506 out of 671 children of which 75.4% had SVI/BL. These comprised CC (35%), RD (24%) microphthalmos (23%). The latter included a high proportion that also had cataract. Avoidable causes included CC, aphakia, amblyopia or postoperative fibrosis. Hereditary disease (retinal dystrophies and congenital cataract with positive family history) accounted for 54.5% and of the hereditary disease cases, 18% were assigned as AD and 57% as AR. The remainder could not be determined because of insufficient pedigree information. There were no significant nutritional causes of SVI/BL seen, neither any cases of ROP which led to the conclusion that the aetiologies were midway between that of the economically most developed nations, and those of the poorest. Cataract screening and treatment was seen as one of the most important preventative measures.

Exactly the same proportion (54%) had been found by Il'ina & Pisarevskii in 1989 in a study of 1843 pupils in boarding schools for blind and poor-sighted children in Uzbekistan; this also identified 87 nosologic forms of hereditary eye diseases. (35), (36)

Consanguinity Rate

The rate of consanguinity in Uzbekistan amongst parents of the affected children was 33.2% in the of Roger's et al study, (4) lower than that found in many Arab countries.

7.6.2 Childhood Blindness in Pakistan and Afghanistan

Introduction

Surveys on childhood blindness in Pakistan are few. (37), (18), (20) The only study on Afghani students is that in Afghani refugees camps in

northern Pakistan. (19) The first study by Sethi and Khan surveyed 61 children at blind schools in Peshawar, Mardan and Kohat; (18) the second was by Butt who examined 234 children in blind schools in Lahore; (20) and the third by Afghani was a cross-sectional survey of children attending 3 schools for the blind in an urban area and registered non-blind school children from a rural area (19)

Causes

Some differences in the causation of blindness existed between the above studies with retinal disorders scored 36%, 41% and 23%.

Whole globe pathologies amounted to 23%, 24% and 23% of cases respectively. Lens disorders (cataract) were reported as 9.67%, 7% and 24% in the three studies respecttively. Corneal disease scored between 19% to 5% in the first two studies, but was not reported in the third. Optic nerve disease was only reported in the Lahore study amounting to 13.11% of the cases, as was glaucoma at 6%.

All the studies showed that heredity was the main aetiology, (18), (19), (20) accounting for 47% of cases, becoming more common in the rural population. Intrauterine factors accounted for 18.03%, postnatal factors 8.19% and cases of undetermined aetiologies for 26.22%.

Consanguinity was high at 50.8%. Family history of the same condition was present in 45.9% of children. The prognosis for vision in 96% of children was poor. (18)

Afghani Children in Refugee Camps

In the fourth study, of Afghani refugees, Awan detected 10 blind children out of 636 examined under the age of 15 years, an overall prevalence of 1.6%. (37)

It was recommended that health education, community surveillance and treatment of affected individuals were priorities, together with training of primary health care workers to detect and treat active trachoma. (37) The absence of screening programme for ROP highlighted the fear that ROP may become a cause of CB in Pakistan. Exact figures on the prevalence of CB from Pakistan are not available, (18) however, its prevalence in south Asia was estimated to be 0.5-1.0/1000. (38)

Night blindness and Bitot's spots (post 3 months of chronic diarrhoea) were found in two children aged 3 years. The author also highlighted the emerging problem of trachoma in the young population as a result of poor hygiene and inadequate waste disposal. The majority of these children lived in households that kept domestic animals in close proximity (within the same compound as the household).

7.6.2 **Childhood Blindness in Bangladesh**

In a large study in Bangladesh involving 1,935 children with SVL/BL, two thirds (69.2%) of the blindness was avoidable. Unoperated cataract was found in (32.5%), and corneal pathology (26.6%). (39) Gender differences were found whereby boys (37%) had lens related blindness and girls corneal problems (29.8%). Acquired blindness was present in 593 children, with 75% attributable to VAD. Access to education and rehabilitation services was exceptionally small and restricted to only 2% of the children with SVI/BL. Whole globe constituted (13.1%).

7.7 **Conclusions**

The above literature demonstrate the variation in the prevalence, and the differences in the causations of CB in the various regions according to their economic development.

The percentage of children in the population is inversely proportionate with the economic status of the country, reaching 50% in the least developed countries. This is paralleled by an increase in the number of blind children in these countries.

Income	High	Middle	Low	Very low
% of <16	20%	30%	40%	50%
Blind children number	200,000	300,000	400,000	500,000
Prevalence /1000	0.3	0.6	0.9	1.2
Blindness per 1million	60	180	360	600
Actiology in %				
CNS/Others	80	55	60	35
ROP	10	25	0	0
Cataract /glaucoma	10	20	20	15
Corneal scarring	0	0	20	50

Table 7.3 Estimates of the magnitude and major causes of childhood blindness according to economies. (43)

In the least developed countries, the prevalence of CB is 4-fold that of the higher income countries. The Table also shows the change in the pattern of diseases contributing to blindness in relation to the economic status and income, so when CNS/other pathologies form 80% of the causation, we find corneal scarring constitute 50% of the causations in the least developed nations with the lowest income. (Table 7.3)

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